



Palliative care is the relief of pain and suffering for individuals living with serious illness. It's a team-based approach, providing an extra layer of support at any age or stage of illness, often together with curative treatment.

The Patient Quality of Life Coalition was formed to advance the interests of patients and families facing serious illness, including survivors. The Coalition includes more than 40 organizations dedicated to improving quality of care and quality of life for these adults and children. The Coalition has developed a consensus-based agenda aimed at promoting public policy that will improve and expand access to high-quality palliative care.

Member groups represent:

Patients
Survivors
Family caregivers
Hospitals
Health Systems
Hospices
Physicians
Nurses
Social Workers
Chaplains
Researchers
Physician Assistants

What is Palliative Care? PatientQualityOfLife.org

The goal of palliative care is to prevent and relieve suffering and to support the best possible quality of life for patients and their families, regardless of the stage of the disease or the need for other therapies. It focuses on relief of the pain, symptoms, and stress of serious illness and on improving communication with patients and families. **Provided by a team of clinicians and specialists** who work with the patient's regular physicians to provide an extra layer of support, **palliative care is appropriate at any age and at any stage in a serious illness**. It can be provided wherever a patient is seen and can be provided together with curative treatment.

Palliative care holds the potential to transform the U.S. health care system and improve quality of life for the over 42 million Americans living today with serious illness and functional limitations – a number that is expected to more than double in the next 25 yearsⁱ. Despite enormous expenditures, studies show that **patients with serious illness and their families receive poor-quality medical care** that is characterized by inadequately treated symptoms, fragmented care, poor communication with health care providers, and enormous strains on family members or other caregivers.ⁱⁱ

By focusing on priorities that matter most to patients and their families, **palliative care has been shown to improve both quality of care and quality of life during and after treatment**.ⁱⁱⁱ Because their needs are met, patients receiving palliative care avoid crises,^{iv} spend fewer days in the hospital, ED and ICU,^v and need fewer readmissions.^{vi} **In fact, studies have demonstrated that high-quality palliative care not only improves quality of life and patient and family satisfaction,^{vii} but it can also prolong survival in certain populations.^{viii}** Palliative care achieves these outcomes at a lower cost than usual care^{ix} by helping patients better understand their needs, choose the most effective treatments, and avoid unnecessary or unwanted hospitalizations and interventions.

The Patient Quality of Life Coalition urges legislative and regulatory change that will:

1. **Advance patient, family, and public understanding** of how palliative care improves quality of care and quality of life.
2. **Develop a well-trained workforce** to ensure sufficient numbers of health care professionals, with appropriate training and skills, are available to teach and to directly provide palliative care.
3. **Invest in research** necessary to establish a strong evidence base for the delivery of high-quality palliative care.
4. **Expand the delivery of high-quality palliative care** in hospitals, nursing homes and community settings through improved data collection, quality measurement, and appropriate provider payment.
5. **Ensure timely access to prescription medication** necessary for effective management of pain and other distressing symptoms in patients with legitimate need.

In the 118th Congress, the coalition will work in support of the following legislation:

The Palliative Care and Hospice Education and Training Act [PCHETA], S. 2243

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ALZHEIMER'S ASSOCIATION
AMERICAN ACADEMY OF HOSPICE AND PALLIATIVE MEDICINE
AMERICAN ASSOCIATION OF COLLEGES OF NURSING
AMERICAN CANCER SOCIETY CANCER ACTION NETWORK
AMERICAN HEART ASSOCIATION
AMERICAN PSYCHOLOGICAL ASSOCIATION
AMERICAN PSYCHOSOCIAL ONCOLOGY SOCIETY
ASSOCIATION FOR CLINICAL ONCOLOGY
ASSOCIATION OF ONCOLOGY SOCIAL WORK
ASSOCIATION OF PEDIATRIC HEMATOLOGY/ONCOLOGY NURSES
CSU SHILEY HAYNES INSTITUTE FOR PALLIATIVE CARE
CAMBIA HEALTH SOLUTIONS
CANCER SUPPORT COMMUNITY
CATHOLIC HEALTH ASSOCIATION OF THE UNITED STATES
CENTER TO ADVANCE PALLIATIVE CARE
CHILDREN'S NATIONAL HEALTH SYSTEM
COALITION FOR COMPASSIONATE CARE OF CALIFORNIA
COLORECTAL CANCER ALLIANCE
COURAGEOUS PARENTS NETWORK
ELEVATINGHOME / VNAA
GEORGE WASHINGTON INSTITUTE FOR SPIRITUALITY AND HEALTH
GO₂ FOR LUNG CANCER
HOSPICE ACTION NETWORK
HOSPICE AND PALLIATIVE NURSES ASSOCIATION
LEUKEMIA & LYMPHOMA SOCIETY
MOTION PICTURE & TELEVISION FUND
NATIONAL ALLIANCE FOR CAREGIVING
NATIONAL BRAIN TUMOR SOCIETY
NATIONAL COALITION FOR CANCER SURVIVORSHIP
NATIONAL COALITION FOR HOSPICE AND PALLIATIVE CARE
NATIONAL COMPREHENSIVE CANCER NETWORK
NATIONAL PALLIATIVE CARE RESEARCH CENTER
NATIONAL PATIENT ADVOCATE FOUNDATION
NATIONAL POLST PARADIGM
ONCOLOGY NURSING SOCIETY
PEDIATRIC PALLIATIVE CARE COALITION
PHYSICIAN ASSISTANTS IN HOSPICE AND PALLIATIVE MEDICINE
PREVENT CANCER FOUNDATION
RESOLUTIONCARE, A VYNCA COMPANY
SOCIAL WORK HOSPICE AND PALLIATIVE CARE NETWORK
ST. BALDRICK'S FOUNDATION
SUPPORTIVE CARE COALITION
SUPPORTIVE CARE MATTERS
TRINITY HEALTH

ⁱ Lewin Group. Individuals Living in the Community with Chronic Conditions and Functional Limitations: A Closer Look (2010)

http://www.lewin.com/content/dam/Lewin/Resources/Site_Sections/Publications/ChartbookChronicConditions.pdf

ⁱⁱ Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. *Journal of the American Medical Association* 7 January 2004; 291(1):88-93

ⁱⁱⁱ Weaver M, Wichman C, et al. Proxy-Reported Quality of Life and Family Impact for Children Followed Longitudinally by a Pediatric Palliative Care Team. *J Palliat Med*, 2018 Feb; 21(2):241-244

^{iv} Hua M, Lu Y, Ma X, Morrison RS, Li G, Wunsch H. Association Between the Implementation of Hospital-Based Palliative Care and Use of Intensive Care During Terminal Hospitalizations. *JAMA Netw Open*. 2020;3(1):e1918675.

doi:10.1001/jamanetworkopen.2019.18675

^v Khandelwal N, Kross EK, Engelberg RA, Coe NB, Long AC, Curtis JR. "Estimating the Effect of Palliative Care Interventions and Advance Care Planning on ICU Utilization: A Systematic Review," *Crit Care Med*, 2015; 43(5):1002-11.

^{vi} O'Connor NR, Moyer ME, et al. The Impact of Inpatient Palliative Care Consultations on 30-Day Hospital Readmissions. *J Palliat Med*, 2015 Nov;18(11):956-61.

^{vii} Casarett DS, Shreve C, et al. Measuring Families' Perceptions of Care Across a Health Care System, *JPSM*, 2010; 40:801-809.

^{viii} Temel JS, Greer JA, et al. Early Palliative Care for Patients with Metastatic Non-small-cell Lung Cancer, *N Engl J Med*, 2010 Aug 19; 363(8):733-42.

^{ix} May P, Normand C, Cassel JB, et al. "Economics of Palliative Care for Hospitalized Adults with Serious Illness: A Meta-analysis," *JAMA Intern Med*, 2018;178(6):820-829.

The Patient Quality of Life Coalition is Chaired by the American Cancer Society Cancer Action Network (ACS CAN)

The coalition is facilitated and managed by AdvocacySmiths, Inc. For more information about the coalition or how to become a member, please contact: Auda Martinez at 703-399-0202 or auda.martinez@advocacysmiths.com